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ABSTRACT

This pilot study used a multidisciplinary, ethnographic approach to evaluate effects of prenatal drug exposure on four cocaine/polydrug-exposed infants and their rural mothers/caregivers and to begin development of a model training program. The study involved document review of hospital and social services records, participant observation, structured interviews, and administration of a test of locus of control and a family needs survey. Specific information evaluated included newborn medical information, demographic information, perceptions of the primary caregiver, and locus of control of caregivers. Findings included: infant complications were experienced by all four children; all four caregivers lived as single mothers; all mothers indicated that a preschool program would be helpful but only one indicated a need for more training herself; caregivers expressed a combination of internal and external loci of control; all caregivers expressed a need to know more about their child's condition; and all believed their children to be normal and healthy. The development of a home-school partnership for educating these children is stressed. Figures and tables detail responses of caregivers. (Contains 15 references.) (DB)

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# RURAL COCAINE/POLYDRUG ABUSING FAMILIES AND YOUNG CHILDREN: AN ETHNOGRAPHIC STUDY OF INTERVENTION NEEDS

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# Rural Cocaine/Polydrug Abusing Families and Their Young Children: An Ethnographic Study of Intervention Needs

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The problem of meeting the needs of cocaine/polydrug exposed children and their families is a complicated, complex, and difficult challenge. We need to add to our knowledge concerning the short-term and long-term effects for the child and family, learn how to ameliorate the effects to the extent possible, and develop model training programs to prepare professionals to meet the challenge. One purpose of this study was to establish a multi-disciplinary group of professionals and begin work on this task.

The investigators conducted a pilot study with 4 cocaine/polydrug exposed infants and mothers/caregivers. Two of the infants were cared for primarily by their biological mothers and two of the infants were receiving foster care. One of the infants was in the foster care of her paternal aunt who planned to adopt her. The other infant in foster care had been in several foster homes during his three years. Data to describe medical information about the drug exposed children, demographics, caregiver locus of control, caregiver psychosocial state of mind, family assessment of early intervention needs, and caregiver's perception of child as sick were collected and examined.

## Problem

Although documentation of the effects of maternal exposure to cocaine/polydrugs on the fetus has progressed, the profile of effects is incomplete. We know that cocaine use by mothers during pregnancy increases the likelihood of spontaneous abortion, stillbirth, abruptio placentae, preterm labor and delivery, birth defects, low birth weight, abnormally high blood pressure and heart rates in the newborn infant, Sudden Infant Death Syndrome, inconsolable crying in the newborn, difficulty in feeding and sucking, distractibility, muscle stiffness that slows growth and development of crawling and walking, irritability and nonresponsiveness, mental retardation, speech and language delays, poor task organization and processing difficulties, poor social and play skills, and attention deficit disorder (Farrington and Peterson, 1991; March of Dimes; Berger, Sorensen, Gendler, and Fitzsimmons, 1990, Los Angeles Unified School District, 1989). According to a document developed by the Los Angeles Unified School District (1989), there is no "typical profile" of a drug exposed child. As cocaine/polydrug exposed children mature, their play behavior and language development appear to be affected. Drug-exposed children display less representational play, more picking up and putting down of toys than curious exploration of toys or combining of toys with fantasy play. Because studies (Bretherton, 1981, Largo and Howard, 1979) have demonstrated a link between representational play and language acquisition, Howard, Beckwith, Rodning, and Kropenske (1989) predict problems in language development for the drug-exposed children at later ages.

Interactions between parents and children are the most powerful experiences promoting children's development. As evidence that experts recognize the impact that parent/child interaction has on the child, a study of 131 Handicapped Children's Early Education Program projects funded from 1982 to 1986 revealed that many of the projects concentrated on interactions between parents and children and the family emerged as the focus of comprehensive services.

Rodning, Beckwith, and Howard (1989) found an increased incidence of disorganized/disoriented attachment patterns among drug-exposed infants. Even for the drug-exposed children who had managed to form secure attachments with their caregivers, the relationship appeared more fragile and less robust than is normally found with secure attachments. This evidence indicates a need to improve the interactions between parent(s)/caregivers and drug-exposed children. Since most drug-dependent mothers have not had an adequate model for parenting, they need to be taught basic parenting skills (Lewis, Bennett, and Schmeder, 1989).

Assessing the child's family and the total home environment is important in order to have a complete understanding of the support available to the child. It is especially "important to identify drug users who may be potential caretakers of infants and children in the home setting (vonWindeguth and Urbano, 1989, p. 151)." If children are seen only in the clinical setting, helpful information about their homes, communities, and the members operating in the homes and communities will be missing.

When a collaboration among the family, the preschool, and the public school is established, the result is stronger interrelationships among the child's various environments which has a positive effect on the child's overall developmental progress (Diamond, 1988). When parents are not taught to fulfill their roles and responsibilities in their child's education program and professionals are not trained to involve parents as full partners, parents are passive participants in their child's education. (Goldstein, Strickland, Turnbull, and Curry cited in Diamond, 1988). Educating personnel in existing programs about the effective involvement of the family of drug-exposed infants is important for the optimal development of these children.

Programs for preparing professionals and future professionals to deal with the needs of cocaine/polydrug exposed infants and their families need to be developed. Professionals need preparation to develop, implement, and manage program components which will or have been identified and modeled.

One model project in Illinois called Project S.A.F.E. ( Substance and Alcohol-Free Environment, begun in 1984) experienced a transition in clientele in 1987 to women who have used cocaine during pregnancy and while parenting (Farrington and Peterson, 1991). Services for the new clientele included the following program components:

1. inter-agency agreements on all levels
2. joint staff training and team building
3. intensive/aggressive service blending, including
   a. aggressive, para-professional in-home service
   b. child care
   c. transportation

d. intensive out-patient treatment (with in-patient referral capability)

e. women's support groups

f. parenting

According to White (Farrington and Peterson, 1991), evaluator for the project, provision of the aggressive para-professional outreach services are the glue that holds the program together and the major agents of change. "In many cases, they are the major therapeutic intervention in our clients mothers' lives. None of these services (child care, transportation, or outreach) are "extras" to be plugged in if another funding source comes up with the cash. They are as much a part of the treatment process as counseling..."

The Los Angeles Unified School District (1989) has identified strategies for bridging the home-school partnership. Suggestions include identificaton of the primary caregiver, scheduling ongoing visits, discussion and modeling of the importance of predictability and organization.

Although experts agree that interagency cooperation and collaboration is essential to meet the needs of the cocaine/polydrug exposed children and their families, cooperation and collaboration are difficult to achieve. Farrington and Peterson (1991) identified the following techniques for overcoming the barriers associated with bringing together different agencies to provide an integrated service continuum:

1. recognize/establish common goals
2. develop formal inter-agency agreements
3. provide joint staff training and team building opportunities
4. pool money and provide service through a lead agency if possible.

The problem of meeting the needs of cocaine/polydrug exposed children and their families is a complicated, complex, and difficult challenge. We need to add to our knowledge concerning the short-term and long-term effects for the child and family, learn how to ameliorate the effects to the extent possible, and develop model training programs to prepare professionals to meet the challenge. This pilot study was intended as an initial step in the preparation of such a model training program.

## Purpose and Rationale

During the last ten years, cocaine abuse has increased steadily in the United States while patterns and frequency of other drugs has remained stable (Chasnoff, 1988). The literature suggests that children born to cocaine/polydrug-abusing mothers may exhibit numerous physiological, behavioral, cognitive, and/or psychosocial anomalies. Polydrug substance abusing family systems indicate vast differences from the norm. Cocaine addicted parents have, as their primary concern, a commitment to chemicals and not their children. In such a chaotic environment and with perinatal exposure to illicit drugs, young children are exhibiting some, if not all, of the following behaviors: (1) difficulty in forming human attachments; (2) low frustration tolerance; (3) easily overwhelmed by information; (4) hyperactivity and distraction if more than one activity is handled; and (5) lack of skills for free play.

This pilot study examined medical data, demographic information from the Department of Social Services records, caregiver locus of control, caregiver psychosocial state of mind, family assessment of early intervention needs, and caregiver perception of the child as sick for 4 cocaine/polydrug exposed infants and mothers/caregivers. The investigators identified specific areas for further investigation of how multidisciplinary interagency services can best be delivered to polydrug exposed toddlers and their families.

## Procedures

### Subjects

The subjects of this research investigation included 2 cocaine/polydrug exposed young children and their biological parent and 2 cocaine/polydrug exposed young children and their non-biological caregiver. Document review of hospital (NICU and Development Pediatrics) and the Department of Social Services records for the substance abusing families and their children, participant observation, and structured interviews are among the ethnographic research methodologies that were used to gather data and profile the participating family systems. Intake information for those children in foster care and for those toddlers whose mothers are enrolled in drug rehabilitation were reviewed. Observers recorded information about each child/mother pair who participated in the study. A structured interview was conducted with each mother for information about her psychosocial state and how she cares for and solves problems concerning her child. Structured home observations and assessment of maternal locus of control (Nowicki and Duke Locus of Control Scale), were collected. Examples of observation instruments are attached. Demographic and other data were collected from the hospital patient records and the Department of Social Services client records.

## Findings

### Medical Information from Patient Records

Prenatal care, length of gestation, method of delivery, APGAR scores, weight at birth, weight at discharge, infant complications, and drug exposure as noted in patient records were examined for all four children in the study sample. Prenatal care for three of the children was poor. Information for one child was not available. The length of gestation was within the normal range for three of the children. One child was born prematurely at 28 weeks. The method of delivery varied widely among the four children. One was an unplanned home delivery, one was vaginal, and two were C-Sections each for a different medical reason. Each child's date of birth, legal custodian, and primary caregiver was also noted from the medical records (Table 1).

A child may score up to 10 on the five APGAR Scale characteristics which are assessed one minute after birth and again 5 minutes after birth. The APGAR scores were available for three of the study participants. The fourth child was delivered at home and no assessment was made. Two of the three children scored low on the first assessment. One of the initial low scorers recovered by the second assessment, however

Table 1

Newborn Medical Information for Cocaine/Polydrug Exposed Sample Members (N=4)

| Sample Member | Date of Birth | Prenatal Care | APGAR | Gestation | Delivery | Custody Caregiver |
|---|---|---|---|---|---|---|
| 01 | 09-29-89 | Poor | No data | 40 weeks | At Home | Grandmother Bio. Mother |
| 02 | 08-13-89 | Poor | 9/9.5 | 39 weeks | Vaginal | Foster parent |
| 03 | 09-11-89 | Poor | 1/6 | 28 weeks | C-Section (abruptio placentae) | Grandmother Bio. Mother |
| 04 | 10-16-89 | No Data | 2/9 | 40 weeks | C-Section (Breech) | Initially in care of mother 10/90 mother incarcerated, child in foster care |

[a]Prenatal Care: One-two visits

Table Continued

Table Continued

Table 1

Newborn Medical Information for Cocaine/Polydrug Exposed Sample Members (N=4)

| Sample Member | Weight at Birth | Weight at Discharge | Infant Complications | Drug Exposure |
|---|---|---|---|---|
| 01 | 6 lbs: 10 oz. | 7 lbs. | supraventricular tachycardia (300 BPM), necrotizing enterocolitis, reactive airway disease, hypertonic extremities jittery: fussy at feedings | alcohol and cocaine |
| 02 | 5 lbs:5 oz. | 5 lbs:15 oz. | supernumerary digits (removed) no withdrawal sym. | cocaine only |
| 03 | 2 lbs. | 4 lbs:10 oz. | abruptio placentae ventilator/respirator surfactant treatment umbilical hernia heart murmur | cocaine only |
| 04 | 5 lbs:13 oz. | 6 lbs:4 oz. | sickle cell trait jittery days 2-10 | alcohol, cocaine, barbituates |

one retained a moderately low score for the second assessment. One of the children had normal scores for both assessments (Table 1).

Weight at birth ranged from 2 lbs. to 6 lbs: 10 oz. Three of the four children had low normal birth weights. One child was discharged from the hospital weighing 4 lbs: 10 oz. Three of the four children weighed between 5 and 7 lbs (Table 1).

Infant complications were noted for all four children. However, two children presented a greater number of complications including supraventricular tachycardia (300 BPM), necrotizing enterocolitis, reactive airway disease, hypertonic extremities, abruptio placentae, ventilator/respirator, surfactant treatment, umbilical hernia, and heart murmur. Only two of the children had withdrawal symtoms noted in the medical record (Table 1).

Drug exposure varied for the four children. Two children had cocaine only exposure. One child had both alcohol and cocaine exposure, and one had alcohol, cocaine, and barbituate exposure (Table 1).

## Child/Primary Caregiver Demographic Information

All four caregivers in the study sample lived as single mothers. The two foster children lived in families with four siblings. In both homes the siblings were biologically related to each other. In one of the foster homes the three children were adopted. The children who were cared for by their biological mothers had fewer siblings. Two children had remained in the care of their biological mother (one with supervision) since being discharged from the hospital. The two foster children had multiple caregivers (Table 2). (One child had six different placements.)

## Primary Caregiver Perceptions

Each caregiver was asked to identify the supports and services they had received and services they needed to care for their child. Only one caregiver (foster) indicated a need for more training. She indicated a need for more information about AIDS. Three of the caregivers indicated little difference between the drug exposed child and their other children. One mother indicated the child had a larger appetite, was more outgoing, and was more demanding. All four caregivers indicated they receive assistance in caring for their children. The support networks for the two foster families appeared to be broader than for the biological caregivers. In addition, the two foster mothers articulated their own previous experience as helpful (Table 3).

Each of the four caregivers indicated that a preschool program would be helpful in preparing their child socially for school. The biological mothers indicated that preschool would assist the children with learning. The foster mothers focused on assistance with social development (Table 3).

## Locus of Control Identified by Caregivers

The Locus of Control Instrument was presented to all caregivers. Locus of control refers to the attribution of achievement, motivation and beliefs pertaining to the sources of reinforcement. Locus of

Table 2

**Child/Primary Caregiver Demographic Information: Data Gathered by Protective Services Supervisor**

| Child's (Date of Birth) | Other Children in Nuclear Family Ages (Sex) (Relationship to Study Child) | Length of Experience as Foster Parent | Single Parent | Length of Time Child has been in Care of Primary Caregiver[a] | Who has custody? |
|---|---|---|---|---|---|
| 01 (09-29-89) | 5 years (Bro)<br>30 months (Bro) | | Yes | 30 months; went home from hospital to grandmother's home; grandmother has custody; child remains with her when there is another adult to supervise | Maternal grandmother |
| 02 (08-13-89) | 6 years (Sis)<br>18 years (Sis)<br>21 years (Sis)<br>2.5 years (Cousin)[b] | 2.5 years | Yes | 24 months; will be permanently adopting | DSS; biological aunt as foster mother |
| 03 (09-11-89) | 6 years (Sis)<br>30 months (Sis)<br>2 months (Sis) | | Yes | 28 months; in hospital 2.5 months; with mother since discharge | Mother |
| 04 (10-16-89) | 4 years (A Sis)<br>8 years (A Sis)<br>9 years (A Sis)<br>2.5 years (F Bro) | 6-7 years | Separated from husband who has very frequent contact with foster mother and children and helps financially | 1 month; DSS had concerns about care child received in previous foster home | DSS; foster mother |

[a]Mean length of time with primary caregiver = 20.75 months

[b]This child is biological niece to foster mother.



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**Table 3**

**Primary Caregiver Perceptions: Data Gathered by Protective Service Supervisor**

| Caregiver | Did you have enough training & preparation to care for child? (source) | Do you receive assistance with child care? (relationship) | How has this child seemed different from your other children? | Do you think a preschool program would be helpful in preparing your child for school? | How? | What is most helpful to you in caring for this child? |
|---|---|---|---|---|---|---|
| 01 Biological | Yes (nurses on maternity floor nursery) | Yes (cousin, cousin's boyfriend, mandatory supervision) | Much bigger; big appetite; more outgoing; more demanding | Yes | Opportunity to be around other kids; enrolled him and herself in parent/child center 2 times per week to help them both learn | Mother and cousin |
| 02 Foster | No (very little information from anywhere was concerned about AIDS) | Yes (sisters, older children) | Not too much; tantrums; aggressive behavior; stubborn; poor balance; walks and runs on tiptoe; lots of ear infections | Yes | Being around other kids would help her develop more. Is on waiting list for Headstart 3 year class. | Experience of raising first 3 children; assistance by older children |
| 03 Biological | Yes (nurses on maternity floor nursery) | Yes (mother) | No | Yes | Help her learn; give her something to do | Help from mother |
| 04 Foster | Yes (Previous experience and DSS foster parent training) | Yes (mother, husband) | No. "He's just a baby." Plays with other kids; learning to talk; off bottle since he came; progressing in potty training; eats and sleeps well; loves attention; friendly but shy | Yes | He would enjoy it; would help him to be away from foster mother; he is now very babyish | Husband, relatives, own experience with children |

control has been found to be developmental - personal causation can be more readily identified with maturation.

Documenting locus of control for caregivers of cocaine/polydrug children indicates to early interventionists where internal and external support exists. A capability to effect change will usually be noted in parents who approach early intervention with an internal locus of control. Feelings of loss may accompany a parent whose locus of control is external.

The following questions were asked of the subjects (Nowicki and Duke Scale, 1974 as cited in Bailey and Simeonson, 1988, p. 156).

| | Yes | No |
|---|---|---|
| 1. Is it better to be smart than lucky? | 2 | 2 |
| 2. Is it hard to change a friend's opinion? | 3 | 1 |
| 3. Good things happen because of hard work. | 2 | 1 |
| 4. When someone doesn't like you, there's little you can do about it. | 3 | 0 |
| 5. Some people are just born lucky. | 2 | 2 |
| 6. You have a lot of choice in deciding who your friends are. | 3 | 1 |

The data suggests that caregivers of substance exposed children represent a combination of internal and external loci of control. Representative figures suggest 13 responses each for the two directions.

**Family Assessment in Early Intervention**

Ascertaining the needs of very young children exposed in-utero to cocaine/polydrugs is a demanding and comprehensive activity. Five reasons exist for making this effort: 1) to meet legal mandates; 2) to understand the child as part of the legal system; 3) to identify families' needs for services; 4) to identify families' strengths that promote family adaptation; and 5) to expand the base for evaluating services.

The Family Needs Survey (Bailey & Simeonson, 1989), an instrument consisting of 35 items organized into six categories, assess parents' need for information related to their child's disability or behavior, how to teach or play with their child, or information about present or future services. The second category assesses parents' needs for support. The third category assesses parents' needs for help in explaining about their children; the fourth category assesses needs related to obtaining community service. Basic living expenses are in the fifth category. And the sixth category assesses the help that might be needed in intrafamily functioning.

All families indicated a need to know more about their child's condition, cocaine-polydrug exposure. Knowledge of how to teach their child, and knowing both present and future needs are noted. Meeting regularly with a counselor was expressed by all mothers.

Few of the 35 items were scored positively by the caregivers ("I need"). Perhaps a lack of awareness exists concerning potential problems caused by cocaine/polydrug exposure both in the present and future. If mothers were not drug free at the time of the interview, their comprehension of the child's

potential development might be impaired. Foster caregivers, in opposition, may see only the progress of their drug-exposed child and not be occupied with negative behavior or intellectual development.

## Do You Consider Your Child's Exposure to Cocaine/Polydrugs a Reason for Him/Her to be Sick?

Talcott Parsons (1951) has observed that while many forms of social deviance condemn the individual to an unconditional exile beyond the social world with normals (children not exposed to cocaine/polydrugs in utero), deviance stemming from physical injury, congenital anomalies, or accident does not. the classic formulation of the sick role includes the following four characteristics (Parsons, 1951):

1. The patient (sic child) is exempted from normal role obligations.
2. S/he is not held responsible for his state.
3. The state of being sick is considered conditionally legitimate if . . .
4. The patient (sic child) cooperates with the source of help and actively works to achieve his/her own recovery.

A fifth characteristic, not explicitly mentioned by Parsons but strongly implied in his formulation, is the presumption that a sick role will be temporary. "Essentially this is a function of deviance being translated into a 'sick role' in which the incumbent (sic child) is viewed as not being able to overcome the condition by his own willpower and is, therefore, not at fault" (Levison & Starling, 1981, p. 375).

The aforementioned sociological theory would be an accessible method to dismiss stigma associated with the moreal deviance, maternal drug abuser. The gross physical anomalies and more subtle learning and/or behavior problems displayed by many drug-exposed children could be attributed to the condition "sick".

None of the caregivers in this study believe their children are sick. The reasons vary but all caregivers indicated their children were normal and healthy (Figure 1).

## Preparing to Educate Drug Affected Children: A Home School Partnership

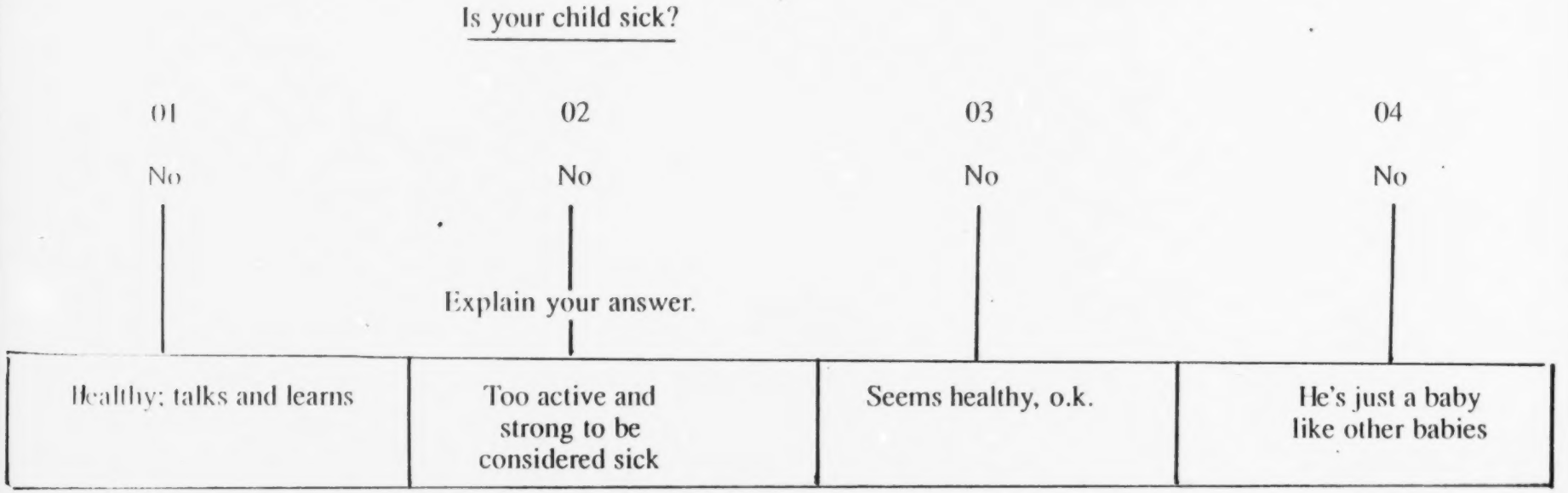
Future school performance from drug affected children is in the process of emergence. Although the infants differed from each other in many ways, most are irritable, have difficulty from being asleep to being alert, have poor task orientation, have gross motor delays, and have problems structuring their play and their relationships (Chasnoff et al., 1989; Howard et al., 1989).

The Los Angeles Unified School District found three major strategies from the preschool program -- transition plans, play, and home-school partnerships. The school social worker develops a relationship with the primary caregiver. As many as 80 percent of drug-exposed infants may live in foster care (Feig, 1990).

Drug exposed children may also need special health and mental health services. High quality child-family intervention services can significantly improve a child's self-esteem, self-control, and ability to solve problems (Los Angeles Unified School District, 1989).

**Figure 1**

**Primary Caregiver's Perception of Cocaine/Polydrug Child as "Sick" (Talcott Parsons, 1951)**



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